

Being Evaluated for Lung Transplant

A Guide for Patients and Their Families



VANDERBILT  UNIVERSITY
MEDICAL CENTER

Vanderbilt Transplant Center

Vanderbilt Transplant Center in Nashville, Tennessee, is one of the South's main providers of solid organ and stem cell transplantation. We offer programs in heart, kidney, lung, pancreas, and bone marrow transplantation, and our outcomes are among the best in the country. Our specialists strive to return every patient to a full and active life. Our mission is to provide end-stage organ failure patients the opportunity to lead extraordinary lives. We thank you for trusting us with your care.

As we treat you, we promise to:

- include you as the most important member of your health care team
- personalize your care with a focus on your values and needs
- work with you to coordinate your care
- respect your right to privacy
- communicate clearly and regularly
- serve you and your family with kindness and respect.

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Overview of the Transplant Process

Your lung doctor (pulmonologist) has suggested that you be evaluated for a lung transplant. For you to decide if you want to consent to this evaluation and transplant, you need to understand both the risks and benefits of the evaluation, as well as transplant surgery itself. Learning about what you are agreeing to is a process called “informed consent.”

This booklet will help you learn what happens when a person gets a lung transplant. This process includes getting approved for new lung (or lungs), waiting for a new lung, and all the other things you can expect before and after surgery.

Why do I need a lung transplant?

A person who needs a lung transplant has lung problems that cannot be fixed any other way. A lung transplant is usually a last-resort treatment for lung failure. Lung transplants may be recommended for patients with any severe lung disease.

Some examples of diseases that may require a lung transplant are:

- cystic fibrosis
- emphysema/COPD (chronic obstructive pulmonary disease)
- idiopathic pulmonary fibrosis
- pulmonary hypertension
- sarcoidosis
- damage to arteries of the lung because of a defect that was present at birth.

What are the steps of a lung transplant?

A lung transplant has 4 major steps:

- evaluation and education
- waiting for a lung
- surgery
- lifelong care and follow-up.

Step 1: Evaluation and education

This first step includes the many tests done to see if you are healthy enough for a new lung. Having all these tests does not guarantee that you'll get a new lung. You will also learn a lot about the transplant process, which will help you decide if transplant is the right thing for you.

During the evaluation and education phase, you will learn about:

- the risks and benefits of transplant
- your surgery plan for either a single- or double-lung transplant
- the alternative treatments to transplant
- the required evaluations and tests you will have done
- the results of all the tests you have done
- how the transplant waitlist works
- how transplant recipients are chosen
- the risks of getting a donated organ, including organ donor risk factors
- any psychosocial or financial issues that may affect your ability to get a transplant
- the strict medical regimen that you would need to follow for the rest of your life after transplant
- current transplant results and outcomes at the Vanderbilt University Medical Center
- your right to refuse to have a transplant at any time—even up until surgery.

Step 2: Waiting for a lung

If tests show that you are healthy enough to get a new lung, and that you meet all other requirements for transplant, you will be put on a waitlist for a donor lung.

Donor lungs are usually from donors:

- who are 10 to 55 years old
- who are legally brain dead. This means their brain damage cannot be fixed. This damage may have been caused by stroke, tumor, or a bad head injury.

Step 3: Surgery

At the time an organ is found, your surgeon will talk to you about the surgery and its risks. At this time, you will be asked to sign a consent form for the surgery. At all times, your health and safety are our main concern.

Understand that there are times when patients are called in for a transplant, but for whatever reason, it is discovered that the donor lung is not suitable for transplant. Although this is disappointing for patients and their families, your health is our main concern.

Step 4: Lifelong care and follow-up

Having a transplant is just the first step in a lifelong process. For the rest of your life after transplant, you will be required to follow a strict medical plan, which will include follow-up appointments and medicines you will have to take every day for the rest of your life.

Do I have any treatment options besides a transplant?

You have the right to decline a transplant as a treatment option. Alternative treatments to transplant include ongoing medical management and options for palliative care.



Can I get a new lung, even with a history of alcohol or tobacco abuse or illegal drug use?

Yes. You may still be able to get a new lung, but you must do the following to stay on the waitlist:

- You must not use alcohol, tobacco, or illegal drugs for 6 months before your evaluation. You will be tested for alcohol, nicotine, and illegal drugs at random during these 6 months. All these tests must show no alcohol, nicotine, or illegal drug use.
- You must not use alcohol, tobacco, or illegal drugs while waiting for your transplant.
- You will complete a tobacco, alcohol, or illegal drug rehab program, if there is evidence that you need to.
- You will be required to be in an ongoing support rehab program. We will require written proof that you are in such a program.

Staying eligible for transplant

To remain eligible for transplant, there are some behaviors you must commit to.

No alcohol, drug, or nicotine use!

To qualify and stay eligible for a transplant:

- no alcohol
- no nicotine or tobacco, including nicotine replacement products
- no illegal drugs
- no abusing or misusing prescription medicines, including narcotics and benzodiazepines.

The Vanderbilt Lung Transplant Program requires that you have 6 months of no use before you begin the evaluation phase and for the entire time you wait for a lung. It is also expected that you will not use drugs, drink, or smoke for the rest of your life after transplant.

The first time you come to our office, we will test you to see if you have any alcohol, drugs, or nicotine in your system. If these tests show that you have been using alcohol, drugs, or tobacco:

- we will re-test you randomly at return visits
- you may be expected to do stop-smoking counseling or another treatment program.

Additional requirements for staying on the lung transplant waitlist

Along with no smoking or alcohol, illegal drugs, or prescription pain medicines, to remain on the waitlist you must:

- keep your weight stable or get down to an acceptable weight range (your target range will be determined by your transplant team)
- be able to walk 750 feet during a 6-minute walk
- stay healthy enough to undergo transplant surgery
- call the Vanderbilt Lung Transplant office every Thursday to check in
- keep your scheduled appointments that will happen every 1 to 2 months with your Vanderbilt lung doctor
- follow all the recommendations of the Vanderbilt Lung Transplant team
- have 2 caregivers to support you
- continue your local pulmonary rehab program
- call the Vanderbilt lung transplant office if you have a temperature over 99.9°F (37.7°C) or you are sick. If you are hospitalized in a hospital other than Vanderbilt, we may require you to be transferred to Vanderbilt for evaluation.

What kind of support will I need through the transplant process?

A successful transplant requires that you have people in your life who are able to give you the support and help you will need. You cannot go through the process alone. For a lung transplant, you need 2 designated caregivers.

The role of your caregiver(s) before transplant:

During your evaluations, you will need 2 caregivers with you.

- Both caregivers will go with you to all your appointments with your social worker, your nurse practitioner, and your surgeon.
- Both caregivers will go with you to your psychosocial evaluation.
- Both caregivers will learn everything they'll need to do for you after surgery, including at the hospital and after.

At the hospital, your caregiver(s) will:

- learn about all your medicines and what they are for, including their side effects
- learn how to take your blood pressure, temperature, and spirometry and oxygen saturation levels and then enter these numbers into your vital-signs log 2 times each day
- learn how to care for your transplant incision as you heal.

By the time you leave the hospital, your caregiver(s) will:

- know all about the medicines you'll take and their side effects
- be able to help you take your medicines exactly how you are supposed to
- be able to help you keep track of the medicines you take by writing in your daily medicine diary the times you take your medicines and the doses you take each time
- be ready to drive you to your lab appointments, clinic appointments, and other visits to discuss your condition with the doctor and report any issues you are having
- have learned about (and be able to help you watch for) signs and symptoms of organ rejection, medicine side effects, or any other medical issues
- be ready to help you with your personal care activities, such as bathing or shaving
- will know how to check your blood sugars and give you insulin injections, if you need them.

At least one of your caregivers must also be ready to:

- be with you when you go back home, if you need them to
- help you get to Vanderbilt for all of your follow-up appointments
- go to your bronchoscopy appointments with you and drive you home from those appointments, since you will be sedated for the procedure.

For three months after you leave the hospital:

- your primary caregiver is required to stay with you 24 hours a day, 7 days a week
- you and your primary caregiver will be required to live within 10 minutes traveling distance from Vanderbilt.



Can I change my mind about having a transplant?

Yes. At any time during the evaluation process, while you are on the waitlist, or just before surgery, you can change your mind about having a transplant.

If you do change your mind...

If you decide that you will not have a transplant, your treatment for lung disease will continue. But you will be taken off the waiting list for transplant. Understand that without transplant, your health is likely to get worse and how long you will live will likely be shorter.

What happens if my transplant fails?

If your transplant fails, you may be eligible for another transplant in the future. This will depend on:

- the reason the organ failure happened
- your state of health.



Transplant Evaluation

What happens during the evaluation stage?

Getting a new lung is serious, risky surgery. You will have many tests, including 2 rounds of medical tests, to find out if you are healthy enough for a new lung. All of these tests will determine if you are medically, surgically, emotionally, and mentally able to go through a transplant. How much social support you have and your financial situation will also be considered.

How long will the evaluation be?

- The evaluation is generally done in 2 phases.
- The evaluation process varies in length for each patient.
- Make sure you bring enough oxygen with you for the entire process.

Will I be admitted to the hospital during my evaluation?

No. Your tests will be done as an outpatient at Vanderbilt University Medical Center. However, if your health deteriorates at any time during your evaluation, we may admit you.

Where should I stay during my evaluation?

You need to have a place to stay in the Nashville area.

Do I need to bring anyone with me to my evaluation?

Yes. You must bring your 2 caregivers with you for your meetings with the surgeon, transplant coordinator, financial coordinator, and social worker. In addition, at least 1 of your caregivers must be with you for the entire evaluation.

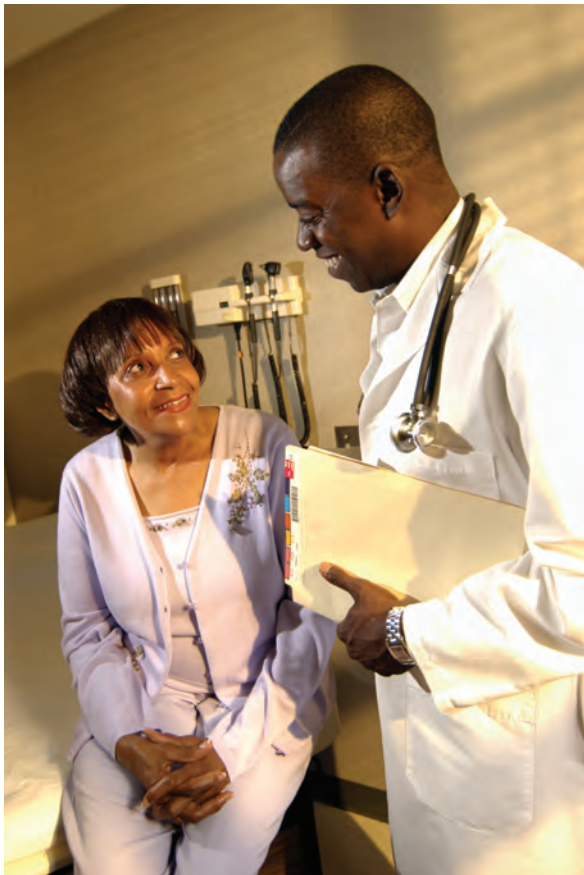
What kinds of medical tests will I need?

Not every person will need all of the tests described in this section, or even the same tests. The tests you have are based on your own situation.

- Every test will be carefully explained in detail in advance.
- If a test has any risks, we will explain all these to you in advance and ask you to sign a consent form which outlines the risks in detail.

Will I see a lot of different doctors during my evaluation?

Depending on your health history, you might see doctors in addition to those on the transplant team. For example, a patient with heart problems might see a heart doctor (cardiologist) during the evaluation, and a patient with diabetes might see a diabetes doctor (endocrinologist) during the evaluation.



Your transplant team

During evaluation, you will meet members of your transplant team:

- nurse practitioner
- transplant coordinator
- social worker
- transplant doctor
- transplant surgeon
- nutritionist
- pharmacist
- psychiatric nurse practitioner.

Your transplant coordinator

Your transplant coordinator will be your partner through the entire transplant process. This person will be available starting from the evaluation stage. You may contact your coordinator any time you have questions or concerns. Everything you talk about is confidential. It will only be shared with the other transplant team members as needed.

Medical tests and consultations

The first tests and office visits you have will tell us about your overall physical health. These tests and visits include:

- a review of your health history
- urine tests
- blood tests
 - We will find your blood type (so you can be matched with a lung).
 - We will check your blood to see if you are immune to or have certain viruses, including HIV (human immunodeficiency virus), hepatitis, kidney function, liver function, chickenpox, Epstein-Barr virus, and herpes
 - We will do tests to screen you for drug and tobacco (nicotine) use.

You will also have these tests:

- tests to see how your lungs are working:
 - pulmonary function tests
 - 6-minute walk
 - chest x-ray
 - chest CT scan
 - ventilation and perfusion (V/Q) scan.
- tests to see how well your heart is working:
 - an EKG (electrocardiogram) to measure the electrical activity of your heart
 - left and right heart catheterization with coronary angiogram to check and see if your coronary arteries have any blockages
 - echocardiogram, which is a sound wave test of your heart.
- tests to measure how well your kidneys work (either GFR DTPA or 24-hour urine collection)
- panorex x-rays of your teeth and jaw.

Dental evaluation

Dental diseases can cause infection or other problems after transplant. See your dentist to be sure that any problems you have are fixed before surgery. You'll need to get a written statement from your dentist showing that any needed work has been done. You'll give this document to your transplant coordinator.

Nutrition evaluation

You'll meet with a nutritionist, who will decide if your diet is as healthy as it should be. The goal is for you to be as strong as possible for surgery. The nutritionist will help you make any dietary changes you need to make.

Risk evaluation

There are many risks that come with getting a new lung. We'll talk about all of this with you in great detail. In addition to the medical risks, getting a new lung has risks that are psychological, emotional, social, and financial.

Psychosocial evaluation

A social worker will meet with you for what is called a psychosocial evaluation. Your designated support person will need to go to this meeting with you.

Your social worker will:

- decide if you are able to understand and agree to the risks, benefits, and expected results of a lung transplant
- discuss the reasons you have decided to pursue a lung transplant
- decide if you and your family are able to hold up under the emotional, financial, and physical stress of lung transplant surgery
- determine if you will have the amount of social support you'll need through the entire transplant process.

Vaccines

- If it has been more than 1 year since you have had a flu vaccine shot, we will give you one.
- If it has been more than 6 years since you have had a pneumonia vaccine shot, we will give you one.
- We will also consider giving you an additional type of pneumonia vaccine and a Hepatitis B vaccination series.

Additional tests

Colonoscopy

If you have not had a colonoscopy in the past 5 years, you will need one.

If you're a male older than 50:

If you are a male and older than 50, You will need to have a recent prostate screening test (called a PSA). You may have the results faxed to the lung transplant office.

If you're female:

If you're female, we will need the results of your last pap smear with HPV screening and mammogram, if they were done in the past year. You can have the results faxed to the lung transplant office.

If you have not had a pap smear or mammogram in the past year, you will need one.

What happens after my evaluation is finished?

If your evaluations and tests show that you are a good candidate for a new lung, and that you meet all other requirements for lung transplant, you will be put on the Vanderbilt Transplant Center Waitlist for a new donor lung. We must be able to reach you at all times while you are listed. Be aware of traveling in areas where you may not have cell phone reception. Let the transplant team know if you plan to travel.

Waiting for a Donor

Where do new lungs come from?

Most lungs come from donors who are legally brain dead. This means their brain damage cannot be fixed. This damage may have been caused by stroke, tumor, or a really bad head injury.

Sometimes lungs can come from people whose hearts have stopped beating.

How are donor lungs chosen?

Good lung function is the most important consideration when a donor lung becomes available. Donor lungs are not matched by sex, color, race, or culture. Organ donation is voluntary. Donation often helps families deal with grief.

Extended criteria donor

If a lung from an extended criteria donor becomes available, your surgeon will talk with you about the risks and benefits of accepting that lung. If you decide not to take that lung, you will not lose your place on the transplant waitlist.

How does the transplant waitlist work?

Your transplant coordinator will explain to you in detail how this waitlist works and how it is decided who gets a lung. There are three issues that are key to offering a donor lung:

- blood type
- body size and weight
- a score called a Lung Allocation Score (LAS) that is based on how sick a person is.

How long does it take to get a new lung?

We have no way of knowing how long you will wait for a lung. It can sometimes take a very long time. It is possible for a patient to die while waiting.

Is there anything I can do to help support my lung and health while I am on the waitlist?

Follow and do everything your health care team says you should do. This includes everything from taking your medicines to eating a healthy diet.

Can I get on the waitlist at other transplant hospitals?

Yes; you have a right to do this. Your transplant coordinator will talk to you about how to get on the waitlist at more than one transplant hospital. You'll also learn how to transfer your listed wait time from one transplant center to another so you don't lose your place on a list.

How is it decided who is highest on the waitlist?

Your place on the lung transplant waitlist is based on your medical needs. The sickest patients are highest on the wait list. A patient's status on the list can change as their health and medical needs change.



Do I need to stay close to Vanderbilt while I am waiting for a new lung?

- It is best if you are within a 4-hour drive from Nashville while waiting for your lung. This is because the donor lung must be transplanted within a 4-hour window to have optimal function.
- If you do live further than a 4-hour drive, you can still get on the waitlist, but you must arrange to have air transportation to Vanderbilt when your donor lung becomes available.
 - It is your responsibility to pay for these costs.
 - Your social worker will give you the contact information for several air ambulance companies.
 - When you choose the companies you will use, give the names and contact phone numbers to your transplant coordinator.

We have program coverage at all times

A transplant surgeon, transplant doctor, and transplant coordinator are available 24 hours a day, 365 days a year to assist with patient management. Back-up coverage is available for each of these people as well. If you ever need help or assistance at any time, a surgeon or doctor can always be on site at Vanderbilt within 60 minutes.

What happens when I get the call for transplant?

You should have your cell phone with you at all times while you are waiting for a transplant. If an organ becomes available, we have only 1 hour to reach you or your support person. If we cannot reach you, we have to move on to the next person on the list. Once you get the call, go directly to the hospital. If it is normal business hours, check into the Admitting Office located in the main lobby of the main hospital. If it is afterhours present to the ER and inform them you have been called in for a lung transplant.

Important reminders:

- Have your bag packed and ready to go at all times.
- Do not eat or drink anything, including water, once you get the call telling you to come to the hospital for your transplant.
- Bring all of your home medicines with you to the hospital as well as a list of your current medicines.
- Remember that there is always a chance that your transplant may be cancelled.

What if Vanderbilt is unable to do my transplant?

If Vanderbilt is unable to do transplants for any reason, such as a natural disaster, we will let you know as soon as possible. If necessary, we will also refer you to another center for transplant care.

At the Hospital

What happens when I get to the hospital for surgery?

As soon as you get to the hospital, we will prepare you for surgery then take you to the operating room.

What happens during surgery?

In the operating room:

- You'll get medicine (general anesthesia) that will make you sleep and keep you from feeling pain during surgery.
- When the anesthesia has started working and you are asleep, the surgery will begin.
 - The transplant surgeon will make an incision in your chest.
 - Through this incision your diseased lung will be removed.
 - The donated lung will be placed into your body, and your incision will be closed.

How long will my surgery last?

Lung transplant surgery usually takes 6 to 12 hours.

What happens after surgery?

After surgery, we will take you to the ICU (intensive care unit). We will watch over you as you wake up and begin to recover. You will have various machines connected to you after surgery:

- Breathing machine (ventilator) with a breathing tube. One end of the tube is connected to the breathing machine. The other end goes into your mouth and down your throat. The machine helps you breathe until you can breathe on your own. It may take 4 to 8 hours to several days before we can remove your breathing tube.
- Chest tubes will be put in your body to help drain blood and fluid from around your lungs. This is necessary for you to begin healing. Chest tubes are usually taken out of your body 5 days after the surgery.
- IV tubes. These tubes go under your skin and into your veins. They are used to give you medicine. These may be in your hands, arms, or neck.
- Urinary catheter. This tube carries your urine from your bladder into a container. It will be removed when you are able to go to the bathroom on your own.

When we feel you are ready, we will move you to a regular hospital room.

How will I feel after surgery?

Pain

After surgery you can expect to feel pain. This may include:

- gas pains
- sore throat
- soreness
- backaches
- incision pain.

For the most part, lung recipients are usually without pain about 2 weeks after surgery. However, some people may have pain for a longer time.

Confusion

You may be confused for a short time after surgery because of the medicines you are taking.

How long will I be in the hospital?

Lung transplant patients are usually in the hospital for 8 to 14 days. However, this may change depending on how sick you were before your transplant and if you had any trouble during surgery. You will be able to leave the hospital when your doctor is confident that it is safe for you to leave.

Can I drive myself from the hospital?

No. One of your caregivers will need to make sure you have a ride from the hospital to your home or the place you are staying in town. You will not be allowed to leave on your own.

When You Leave the Hospital

When you leave the hospital, you will still be recovering. Because of this, you will need to stay within 10 miles of Vanderbilt for at least 3 months after your surgery. At least one of your caregivers will need to stay with you for this entire time.

Depending on your circumstances, your recovery time may be even longer. Your lung doctor (pulmonologist) or transplant coordinator will tell you when you can go home.

Short-term care

Your short-term care will include:

- appointments with your doctor to check on your new lung
- blood work and other tests to see how your lung is doing.

Long-term follow up with the transplant team

Every effort will be made to transfer your regular medical care to your primary care doctor. However, the transplant clinic will still follow you for the rest of your life.

This follow up typically involves:

- frequent lab work
- a clinic visit at least 1 time a month for the first year
- yearly studies that will be done around the same time that you had your transplant. This testing usually takes about 2 days.

If you have any complications, the transplant team may need to see you more often.



Risks and Possible Complications of Transplant

How successful will my transplant surgery be?

A lung transplant is complex and the risks are high, including the risk of death. Your doctor cannot know exactly how your body will respond to a transplant until it happens. We never really know how the problem that caused your original lung problems will affect your new lung.

The success of a lung transplant will also be affected by:

- how sick you are before your surgery
- how well you follow the complicated treatment plan prescribed by the transplant team.

What are the risks associated with a lung transplant?

Risk of interrupted surgery

Sometimes a surgery is cancelled. This can happen if the surgical team decides you are too sick for transplant or if the donor lung is not healthy enough to use.

If your surgery is cancelled:

- you will return home and continue to wait for a new lung
- you will not lose your place on the waiting list.

Risk of rejection

The chance that your body will reject your new lung is always possible.

The risk is highest the first year after your transplant. The good news is that rejection is usually treatable. Treatment may be provided at home or may require that you go to the hospital.

Your body will never develop a tolerance to your new lung. This means that for the rest of your life you will have to take medicine to keep your immune system from attacking your lung.

Risk of complications from your lifelong, anti-rejection medicines

Anti-rejection medicines are critical to preventing organ rejection. You will take them for the rest of your life after transplant. However, these medicines do have potential complications, including:

- increased risk of cancer
- high blood sugar levels
- damage to other organs, including your kidneys
- high blood pressure
- increased risk of infection
- increased risk of bone disease.

Risk of pain, bleeding, or injury

Transplant surgery can cause pain, bleeding, or damage to other organs in the belly.

Risk of sickness or infection

This surgery can cause sickness and infection, including:

- feeling sick to the stomach
- fevers
- pneumonia
- infections of the bladder
- infections to other organs in the chest.

Risk of blood clots

This surgery may cause you to have blood clots in your legs. This is dangerous since clots can travel to your lungs and make it hard for you to breathe.

To help prevent blood clots, we may put plastic boots or other special devices on your legs. These devices are designed to inflate and deflate around your legs. By gently squeezing your legs, they help keep the blood in your legs flowing well both during and after surgery.

Risk of nerve damage

This surgery can cause nerve damage, which can cause numbness, weakness, paralysis, or pain in your body. Most of the time these symptoms last only a short time and go away on their own. In rare cases, they can last for extended periods or even become permanent.

Increased cancer risk

You will have a slight increase in the risk of getting certain kinds of cancers (skin and some lymph cancers). This is caused by the medicines you will take for the rest of your life to keep your body from rejecting your new lung.

Risk of disease or infection from the donor

The risk of catching a transmittable disease or infection from a donor is very rare. Before donation, all donors are tested for transmittable diseases and infections, including the HIV, Hepatitis C, and Hepatitis B viruses. However, no organ transplant is completely free of risk.

Even though all donors are tested, there's a small chance they may have an infection, even if tests say they don't. One way this can happen is when a donor had an infection that was very recent and doesn't yet show up on a test.

The risk of missing an infection is low. It's about 1 in 10,000 to 1 in 1,000,000 depending on the risk criteria. We'll always tell you if there's a chance a donor had a risk of exposure that testing could have missed.

Risk of death

As with any surgery, there is the risk of death. This is especially true with lung transplant surgery given how serious it is.

Anesthesia risks

Your surgery will be done under general anesthesia. The anesthesia will make sure you sleep and feel no pain during surgery. General anesthesia has a number of known risks. An anesthesiologist will explain all of these risks to you. In order to have surgery, you will be required to sign a separate consent form showing that you understand the risks of anesthesia.

Risks of blood transfusion

You may need to receive blood during or after surgery. Even though all blood is carefully checked for HIV, hepatitis, and other diseases, anytime you receive blood, there is the risk of being infected.

Risks associated with pregnancy when you are taking transplant medicines

There are some transplant medicines you should never take if you are pregnant or actively trying to become pregnant. These include mycophenolate mofetil or mycophenolic acid. These medicines may increase the risk of birth defects or pregnancy loss.

- If you are a woman of childbearing age who has not had a hysterectomy, you must use 2 acceptable forms of birth control. Talk to your doctor about the best birth control options for you.
- If at any time you want to try to become pregnant, talk to your doctor in advance so you can begin taking alternative transplant medicines. Never stop taking any transplant medicines without talking to your doctor first.

Risk of additional complications

Across the country, the risk of having some kind of complication (major or minor) from a lung transplant is more than 30 percent. Most problems get better. However, sometimes, another surgery or procedure may be needed.

Possible risks and complications in addition to those already discussed in this booklet include:

- injury to structures in your belly
- pressure sores on your skin caused by the position that your body was in during surgery
- burns caused by the electrical equipment used during surgery
- damage to your arteries and veins
- heart attack
- stroke
- seizures
- a permanent scar where your surgical incision was made.

Psychosocial risks

Having a transplant can be very stressful emotionally and psychologically, as well as physically. After transplant, there is the risk you may develop psychosocial health problems, including:

- depression
- post-traumatic stress disorder (PTSD)
- generalized anxiety
- anxiety about having to depend on others
- feelings of guilt.

There are many resources to help you if you have any of these issues. Let us know if you need any help at any time.

Financial risks

Getting a transplant can affect you financially, both now and in the future.

- During the evaluation process you may find out that you have some health problems that you didn't know about.
 - You may have to spend money to treat these problems.
 - Some of these problems could also affect your ability to get health or life insurance, depending on what they are.
- Getting a lung transplant may affect your ability to get life or health insurance in the future. Insurance companies may identify you as having a pre-existing condition and refuse payment for medical care, treatments or procedures.

Common Medicines for Transplant Recipients

As a transplant recipient, you will need to take various medicines for the rest of your life. You will get medicines to help your body accept your new organ. These are known as “immunosuppressive drugs” or “anti-rejection medicines.”

After transplant, patients usually go home taking 2 or 3 types of anti-rejection medicines. This is in addition to their other medicines. Anti-rejection medicines help your body accept the transplanted organ by lowering your body’s natural reaction, which is to attack foreign tissue. At first, you will take large doses of these medicines. The amount you take will gradually be lowered as your body accepts the new organ.

It is important that you ALWAYS take your medicines exactly as directed.

- You need to know the names of these drugs, how much you are taking, and what the pills look like.
- Your nurse will help you and your support person learn all about your medicines so you can take them yourself in the hospital and at home.
- Failure to take these drugs or skipping doses can cause your body to reject your new organ.
- It will be necessary for you to take all your medicines on a strict schedule.

Common medicines

The 3 most common anti-rejection medicines for transplant patients are:

- Tacrolimus (Prograf)
- Mycophenolate (Cellcept) or azathioprine (Imuran)
- Prednisone.

These medicines work well at lowering rejection risk, but also have a number of possible side effects, including:

- lower ability to fight infection
- increased risk of certain cancers
- increased risk of birth defects
- nausea or diarrhea
- high blood sugars.

There are additional side effects as well. We will talk with you about them.

After transplant, you will have to take anti-rejection medicine for the rest of your life. Once you are transplanted, we will give you more detailed information about the specific medicines you will be on and instructions on how to take them.

Your Life After Transplant

Prevent infection

The medicines you will take for the rest of your life will make you more prone to getting infections. The good news is that with good habits, you can stay healthy.

Some of these things you will need to do for the rest of your life. Other restrictions may be lifted in time. Your transplant doctor or nurse will tell you when some of these restrictions may be lifted.

Tips to prevent infection:

- Stay away from people who are obviously sick with the flu or a cold.
- Try to avoid children with chicken pox or strep throat.
- Wash your hands with soap and water before you eat and after you go to the bathroom.
- Shower or bathe regularly. Wash your incision as you would any other part of your body. Do not use lotions or powders on your incision.
- Clean cuts and scrapes right away with soap and water; then apply an antiseptic and a bandage.
- Do not, under any circumstances, change the litter in the cat box or birdcage without wearing gloves. This could cause a serious infection. Avoid cat scratches.
- Do not garden, dig in the dirt, or mow the lawn after your transplant without wearing a mask and gloves. Not wearing either one of these could cause you to get a serious infection.
- Keep your fingernails and toenails clean and trimmed. If your toenails are hard to manage or are ingrown, see a foot specialist.
- Talk to your doctor about getting the flu and pneumonia vaccines. Neither of these vaccines contain live viruses. Both vaccines are safe for you to have.
- Do not get any vaccine that contains a live virus, such as the smallpox or polio vaccine.
- Talk to your doctor if someone in your house is going to receive a live virus such as the oral polio vaccine or diphtheria vaccine if you have not already been vaccinated.
- Do not smoke. And do not expose yourself to second-hand smoke.
- Avoid community whirlpools.
- Avoid swimming in lakes or ponds.



If you want to have a child

Women

Women who have had a lung transplant have an increased risk of having complications related to pregnancy. These risks are increased for both herself and the baby.

For this reason, women should avoid becoming pregnant after transplant.

Men

Although men may father children at any time after transplant, talk to your doctor before trying to conceive to be sure the medicines you are taking, such as mycophenolate, will not affect the baby.



Medicare and Financial Considerations

If I have Medicare, can I have my transplant at Vanderbilt?

Vanderbilt Transplant Center is currently Medicare-approved. However, the center is audited every 3 to 5 years for continued approval. If Vanderbilt lost its Medicare approval, Medicare would no longer pay for transplants at the center. We will keep you informed about our status. If we become deficient in any Medicare requirements at any time, we will let you know.

Paying for your medicines

Without your proper medicines, your body will reject your new organ. You will need to be able to pay for your medicines or have enough prescription drug coverage at the time of your transplant. Without adequate drug coverage, your estimated costs for your medicines are about \$5,000 a month (\$60,000 a year) for the rest of your life. Because these costs are so high, it is important that you inform us of any changes in your drug coverage. It is also important that you always have pharmacy coverage.

If Medicare pays for your medicines

If Vanderbilt Transplant Center ever loses Medicare-approved status, your ability to have your immunosuppressive drugs paid for may be affected. Our financial counselor will talk with you about these details so you can make the best decision for you.

Fundraising

If you anticipate that you will have any major costs that may not be covered by your insurance (including prescription co-pays, travel, and lodging), we encourage you to consider doing some fundraising. Call the numbers below and to begin the process of fundraising as soon as possible.

These organizations have been able to make quite a difference in the lives of many of our patients. They are often able to help patients before, during, and even years after their transplants.

Two organizations that help transplant patients raise money:

- NFT (National Foundation for Transplants): (800) 489-3863
Transplants.org
- Help Hope Live (Formerly National Transplant Assistance Fund): (800) 642-8399
HelpHopeLive.org

Your financial coordinators

Your financial coordinators will keep everyone at Vanderbilt informed about your current insurance coverage, will get all the necessary authorizations and approvals required from your insurance throughout the process, and will help you in any way possible with your insurance questions and concerns. We know this can be a lot of information to process all at one time. Please don't hesitate to call us.

Notify your financial coordinators immediately if:

- you begin or end the coverage you have through COBRA
- you obtain any new insurance
- any of your current insurance policies change or end
- there are any changes in your Medicare Part D coverage.

Learn more:

- Medicare
Medicare.gov
- Centers For Medicare and Medicaid Services (CMS)
CMS.gov
- Social Security Administration
SSA.gov

Resources and Patient Tools

United Network for Organ Sharing (UNOS)

You may get more information about transplantation from UNOS.

- The UNOS website: **UNOS.org**.
- The UNOS toll-free patient phone line: 1-888-894-6361. This phone line can be used to:
 - help transplant candidates, recipients, donors, and family members understand the way donor organs are matched with the patients who need them
 - find information, data, and statistics about transplants
 - to talk about any problems you have at your transplant center or with the overall transplant system.

National and local transplant data

During your evaluation meeting, your transplant coordinator will give you copies of the current data about national and Vanderbilt-based transplants. This information will help you learn about the number of transplants performed both nationally and at Vanderbilt, including the results of the transplants.

Information sharing

As you go through the transplant process, members of your transplant team may access and share your medical information as permitted by law and Vanderbilt University Medical Center policies.

If you do end up getting a new lung, information about you, which will include your identity, will be shared with UNOS. This information may also be sent to other transplant-related agencies or companies as permitted or required by law.

Information sharing is an important part of overall transplant program success, both nationally and locally. As a person who gets a transplant, it is expected that you agree to postoperative and long-term follow-up tests with the knowledge that this information will be shared.

Learn more:

Lung Transplant Foundation
[LungTransplantFoundation.org](https://www.lungtransplantfoundation.org)

Coalition of Donation
[ShareYourLife.org](https://www.shareyourlife.org)

National Foundation for Transplant
[Transplants.org](https://www.transplants.org)

National Transplant Assistance Fund
[TransplantFund.org](https://www.transplantfund.org)

United Network of Organ Sharing
[UNOS.org](https://www.unos.org)

Vanderbilt Lung Transplant Program
[VanderbiltHealth.com/Transplant](https://www.vanderbilthealth.com/transplant)



